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TIPS

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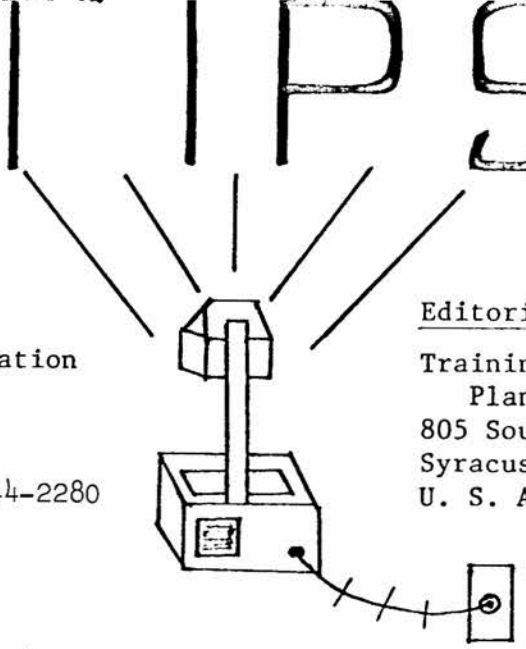

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Social Advocacy

"They are slaves who fear to speak
For the fallen and the weak..."

This issue of TIPS is devoted to the topic of social advocacies in the plural, by which we mean a person, group, or organization speaking and acting on behalf of another person or group in order to promote or defend that person or group's welfare. Social advocacy can be informal or formal, it can be engaged in by individuals or organizations, it can be long-term or short-term. Usually, the person or group on whose behalf the advocacy is practiced is devalued or disadvantaged. In this issue, we hope to sing the praises of social advocacy as an ideal, share some stories of successful advocacy and inspiring advocates, acknowledge some shortcomings and perversions of advocacy and point to some advocacy needs. We hope that TIPS readers will be inspired to engage in some form of social advocacy, if they are not already doing so.

Advocacy-Related Bodies or Thrusts

*A 1978 amendment to the Older Americans Act required the establishment of a long-term care ombudsman program in each state, and regulations issued in 1980 and 1981 required that area agencies on aging carry out activities and support of state ombudsman programs. Such a development is good in principle, though one bad part about it is that it uses the name ombudsman, which really should be reserved for reference to a fully independent office that has no other responsibilities. One good element is that states, local government, and private sources have contributed funds, 75% being federal. According to a report on the status of the ombudsman program for 1981, there were 43 state-level programs, 407 full-time and 56 part-time workers, and 1765 volunteers. Nearly 40,000 complaints were received from or on behalf of elderly persons in long-term residential facilities. One state alone had 10,000 complaints. Resident care issues topped the list (Aging, 1-2/83).

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*An example of a communal support service is Extend-A-Family that got started in Toronto in 1975, which offers loving care in a home and community environment to any young person with a handicap while also giving parents a needed period of relief. The communal element here is underlined by the fact that it is often the same families who support the same family with a handicapped child, and that many members of the program, both those who provide the support and those who need it, know each other over a period of years (e.g., The Human (6), 1984). Similar services have gotten started in many other localities in North America.

*Gerretsen Productions is Canada's leading producer and distributor of educational programs on human life issues. The Gerretsen husband and wife team began making films on human life issues in 1977. The films are noted for their dramatic or comic treatment of the subject.

*You would never guess what the Committee Against Racism and Tackiness (CARAT) is all against. It goes around at night and steals statues of jockeys with black faces from people's front yards. While they are certainly a most peculiar social action group, their goals must be lauded.

David vs. Goliath: (Mostly Uplifting) Advocacy Vignettes

The Rapid Radicalization of a Citizen Advocate

Terry is a young woman who has been bounced back and forth between a group home and an institution for the mentally retarded in Manitoba. Rebecca is her citizen advocate. They were interviewed by an interviewer (indicated by Int. below) about their experiences, and the interview (excerpted from Citizen Advocacy Manitoba Newsletter, 5/83) makes a telling vignette of how the service super-system can act in such a gross fashion as to rapidly radicalize an advocate.

Int: What did you know about Terry before that first meeting?

Rebecca: Well, I was told that Terry was a young woman around 26, that she had quite a bit going for her....I knew she was living in a group home and she wasn't very happy there. I knew that on a couple of occasions when either the group home or her social worker didn't like the things that she'd done, they'd taken her out of the city and taken her to an institution in Portage la Prairie for a while....That was the main thing that shocked me and scared me because I didn't really....I was totally shocked. I didn't think things like that happened. I figured that all people in this country were people and that all people had some basic human rights and that they couldn't just be picked up and deported or sent away.

Int: So did you get involved because you wanted to fight the system?

Rebecca: No, I was scared to death of fighting the system. I didn't know how to fight a system. I guess after hearing this I...felt very inadequate to deal with it but was...being encouraged to be a friend with Terry because she really needed someone and I figured that even if I couldn't do anything else for her, or make her life better, I could at least share her misery.

Int: What did you expect a relationship to be before you got involved in it, before you met Terry? And even after that period where you had that first lunch with her?...

Rebecca: I don't really think I had any clear expectations. The first thing I wanted to do was to get to know Terry as a person a little bit before we started dealing with any of her problems.

Int: You didn't want to fight the system?

Rebecca: Well, I didn't....The reason I became interested in CA wasn't because I had any great urge to fight the system, it was because I wanted to be involved with another person.

Int: Then what did you think that you were going to have to do about those problems?

Rebecca: It seemed to me that the things that needed doing were clear. I didn't think that...she should just be taken and shipped off to Portage--I thought that would have to be changed. I thought she would need a better place to live.

Int: Where would you fit into that?

Rebecca: I think I saw myself at that point as probably encouraging her social worker and working through her social worker to find her a place to live. That really wasn't the way it turned out.

Int: What did happen?...

Rebecca: Well, first I guess I should tell you about the trouble I had becoming Terry's advocate. I phoned her at the group home and introduced myself to the lady who managed the group home and I said, "Hi, my name's Rebecca and I'm going to be an advocate for Terry and I'd like to take her out tonight and maybe stop over and meet you." Immediately she told me that I really had no right to be Terry's advocate and that in order to associate with Terry I had to get cleared through Community Services and through the person who was the head of the organization that ran the group homes. So I figured that if that's what I had to do then that's what I'd have to do. So, the next thing I did was, I got in touch with the person who ran the group homes and went down there with the CA coordinator and tried to talk her into letting me be a friend to Terry. I wasn't being radical, all I was saying was I'd like to be a friend to Terry and take her out a couple times a week, do things with her....She said, "No, I can't give you permission to do this. It has to be cleared through other people. I can't let Terry associate with people unless they're cleared by (provincial) Community Services." So, I was quite shocked because I figured that Terry being a person had the right to make friends and to see friends once in a while. I could sort of understand it if I had a real bad reputation or if they had some real reason to think that I was going to harm Terry or something, but I was just a nice person, so I thought. I guess they were getting kind of defensive because of all the things that had happened to her. If I was in their shoes I would have felt pretty bad. So anyway, she told me that she couldn't give me permission to see Terry. I was allowed to talk to Terry over the phone. So then I went to Community Services and I was interviewed by some guy there. He...asked why I wanted to be an advocate. I still wasn't cleared. I was told I had to write a formal letter asking to be an advocate to a Regional Director of Community Services, so I did that. This guy told me it sounded fine except I'd have to get the approval of the Public Trustee (the public guardian). So I went and I was interviewed by two representatives of the Public Trustee who seemed to think I was all right. Then after that I think I had one interview and I met the Public Trustee. Nobody had any reason why I couldn't be friends with Terry, they just didn't seem to want me around.

Int: It sounds like the rest of the system didn't know what was going on from one part to another.

Rebecca: Well, I think the rest of the system knew what was going on, I think what they were basically doing was just using stall tactics, because they knew quite well that there were a lot of people in the community that weren't very happy with what they'd done to Terry. There were a lot of people around who weren't very happy with the way they'd taken her out to Portage. At one time they removed her from work and took her out there, so I think that there was stall tactics being used. I can't think of any other explanation.

Int: Where does CA fit into the whole picture then? Why the unwillingness to be open to the involvement of CA?

Rebecca: I don't know. I guess that agencies who deal with handicapped people would rather have the power to do whatever they want with them and not have anybody question it.

Int: Where does that leave the handicapped person?

Rebecca: Up the creek.

Int: It sounds like it. So finally, after the group home person, and the community services and the Public Trustee...we've still got more?

Rebecca: I wrote at least two letters and I had several interviews to be Terry's friend. The other thing was they wanted me to sign a paper saying that when I was with her I would be responsible for her and all this other stuff, I wouldn't take advantage of her or anything. This paper, what it would exactly say is still being hassled over, so they gave me permission to see Terry before the paper was signed....They still haven't got this paper together. Terry and I have been associating for quite some time. Anyway, we finally were allowed to see each other...

Int: And what you wanted to be was a friend?

Rebecca: Well, yeah, what I wanted to be was a friend, but I guess if you have a friend who's got a problem you help your friend out and sometimes if your friend needs somebody to stick up for them, if my friend needs someone, I don't run away on them. In any relationship if you're a friend, there are times you're gonna stand up for them and help them, and I think if your friend has a handicap then maybe they have problems because no one listens to them and they might need their friend to be an advocate more than most people would.

Int: You were walking into, what I consider, advocacy right from the start. How did it feel? Where did you see yourself in that system? You were already beyond friendship.

Rebecca: Where did I see myself? I saw myself as a pain in the rear. In terms of being an advocate I guess I saw myself as representing Terry and trying to get in her life the changes that she wanted that she wasn't having much success in getting for herself. I guess as an advocate I saw myself speaking for her or speaking with her.

Int: Terry, what were the changes you wanted in your life at that time?

Terry: Kind of like, freedom, doing things I want to do, but they said, no, you can't do what you want. I said, no, I want to do what I want.

Int: Were the things you wanted to do really bad? What were they?

Terry: To go out, do different things with different people, things like that and they said, "We're running your life." But I don't want them to run my life. I want to run my life myself.

Int: Do you have any idea why they wanted to run your life?

Terry: So I don't get hurt, so I don't get killed, or things like that. I don't know.

Int: Was that the end of it?

Rebecca: No, they let me start seeing Terry before I signed a paper that I still haven't signed, the paper is still in the making.

(In the following part of the interview, the advocate told how Terry was several times kicked out of the group home and taken to the institution as a punishment, even out of her day work situation, and how the advocate was deeply embarrassed because she was told it would not happen again, gave her word to Terry that it would not--and then it did happen again. She thereupon invited Terry to live with her and her husband for a while, and then helped her find a place in the Prairie Housing Cooperative as described in the June 1983 issue of TIPS.)

Int: I'd be interested in finding out a little more what kind of support you got.

Rebecca: Terry had problems and I didn't know what to do about them and Terry didn't really know what to do about them either, so I got ideas about what I could do and there was always somebody there (from the CA office) with me to go to meetings if I needed somebody beside me. I just got moral support. I had somebody to talk about things with.

Int: Rebecca, where do you see things going now?

Rebecca: I don't know, I think during these past few months, my relationship with Terry has been very intense, we've been living together, but I think from this point on, she's going to be having her own life, more than she has been, but our friendship will continue. I hope that me and Terry will be friends for a long time. I guess we'll be spending less time together. In a way, it's good the way it's happened. It seems like it's a natural thing the way things should go, for a while I was giving her a lot of help because that's what she needed, but now she's become more independent and stronger and she's got more of her own life now, developed more relationships with other people. So I think she's sort of ready to go out and get her own place and I'll still be there to help her, she'll still be there to help me, too, when I need a friend.

(Once Terry had settled into her apartment together with another handicapped friend and the help of her advocate and members of the co-op, she became so busy doing so many things, and able to do so many things alone, that she and her advocate see less of each other.)

*In Georgia early in 1984, a mentally retarded woman was evicted from the boarding home in which she lived, and put into a nursing home. An advocate was found for her who began to try to get her into a group home in the community. Before the woman entered the nursing home, she had to have a complete physical, at which she was given a clean bill of health, and she had to have another one before entering the group home, even though it had only been two months since her previous physical. Ordinarily, we decry this sort of objectified, formalized human service policy which is so often wasteful. However, in this case, it turned out to be life-saving. At the second physical, it was discovered that the woman had been fitted with an IUD (contraceptive) some years before--most likely, when she was first deinstitutionalized--though there was no record of this ever having taken place, and it had never been checked. The woman had become so infected from this device that antibiotics were not sufficient to destroy the infection, so she had to have a hysterectomy. So pervasive was the infection that the entire operating room had to be decontaminated after the operation. The woman was probably in severe pain, but was on such large doses of psychoactive medication that she was probably unable to report it--yet one more example of how psychoactive drugs can reduce people's ability to report danger signals, and thus lead indirectly to their deaths. Furthermore, nursing home personnel should have known that something was wrong, since the woman was having uninterrupted menstruation, though this was only reported to her advocate once she left the nursing home.

One shudders to think what would have happened to this woman had she not had a strong advocate. (Vignette submitted by Barbara Fischer)

*A woman who had lived in a nursing home for 14 years was finally able to move into a group home, thanks to the efforts of her advocate. However, before entering the group home, she had to have a complete physical, at which it was discovered that she had pre-cancerous cells in her mouth and needed a great deal of dental work. (Remember, she had lived for 14 years in a setting that claims to be medical in nature, and to provide needed medical care!) The needed work would cost thousands of dollars, but Medicaid/Medicare pays only for tooth extraction, not for corrective work. If her advocate had not been successful in getting her moved out of the nursing home, the cancer in her mouth might never have been discovered, or at least, would not have been discovered until it was too late. (Vignette submitted by Barbara Fischer)

*A middle-aged mentally handicapped woman was evicted from the private boarding home in which she was living, and was to be placed in a nursing home. An interested service worker informed a citizen advocacy office, and an advocate was recruited to prevent the woman's move into an institution. The advocate filled out an application for the woman to enter a group home (none of the service workers responsible for the woman had apparently thought of this), and although the move to the nursing home was not prevented, it only lasted for a short period of time while her entry into a group home was pending. However, while the woman was in the nursing home, she was not permitted to continue to attend her day program. The reason? That would constitute "duplication of services" since both the nursing home and the day program received Title XX monies. Fed up with this situation, the advocate found an ordinary citizen who welcomed the mentally handicapped woman into her own home where she could continue to live and be involved in her day program until she could move into the group home.

This kind of incident is certainly not unique, and it illustrates a number of points, including: the very limited and limiting mindset of most paid human service workers, who can only conceptualize formal, organized, and usually institutional service options for people in need, the much greater and quicker effectiveness of unpaid citizen volunteers who are not under the constraints of the service super-system; the absurdities of our human services which create disincentives to doing the right thing (e.g., the prohibition for the woman to continue to be involved in productive activity during the day when she entered the nursing home).

*Below follows an obituary written by Bill Nichols in Sydney, Australia, for a retarded man for whom he served as a citizen advocate, and first published in the (Western Sydney) Citizen Advocate, 10/83.

He was a little man--physically almost unsafe in a high wind, mentally so retarded as to contribute nothing to a group, emotionally, fifty-seven years of being ordered or ignored had reduced him through inferiority to abject dependence.

That was Tom five months ago, when I undertook his advocacy. Our first outing was a disaster--I tried too hard, expected too much. Tom felt overwhelmed, inadequate and ultimately ashamed, I felt appalled, then confused. Subsequently, we stuck to Tom's favourite meal--a Big Mac. He became more trusting, looked forward to our meetings. He learnt to greet our waitress, Carmen, who was always kind and patient as Tom struggled to order, afraid to make even the simplest decisions.

Tom improved but I am not a patient man. He perceived that making a gesture of compliance to my requests, failing and looking helpless, ensured that I would do what was needed. I felt merely another prop to Tom's dependence--an authority figure shouldering his responsibilities without punishment or scolding.

Saturday we enjoyed the local advocacy office's Birthday Barbecue. There Tom showed unwonted memory, co-ordination and dexterity operating a hand dryer. Encouraged, I envisaged strategies to develop this independence. Tuesday Tom was part of a hospital barbecue in a rugged National Park area, enjoyed his steak, then wandered off. He was missing at departure time--still missing hours later when helicopters, Rescue Squads, Rangers and other searchers were recalled for their own safety. Wednesday morning Tom's body was found, his face peaceful, at the foot of an escarpment.

A sad story, but not all tragedy. Tom seemed little, but in acceptance of his disabilities, was a giant. He was a good man, hurting no one, living only to please. Association with him made us better, wiser, more tolerant people. I shall not forget Tom Burgess. May he rest in that peace he never knew in his lifetime.

*Marsha Forrest, a visiting scholar at the (Canadian) National Institute on Mental Retardation in Toronto, knew a 33-year old retarded man who was illiterate and who had been told all his life that he would not be able to learn to read and write. Through a program of adult education at Frontier College in Toronto, similar to that sometimes called College for Living, literacy education was provided to him, and astonishingly, in only two months, he was able to read fairly well and write letters well enough to communicate everyday phenomena and aspirations. In fact, he was able to read well enough to understand news stories in Time.

*Few professions have craved as much for power as has medicine. A major ideology of the profession has been that medicine should function without any external restraint or review, and that it should be able to exercise total control over people who seek its services or upon whom medical services are imposed by third parties. One of innumerable expressions of this ideology has been the claim of psychiatrists that they are entitled to administer psychoactive drugs to their clients without the clients' informed consent, and that even residents voluntarily admitted to state mental institutions can be put on psychoactive drugs against their will. Many of these drugs are extremely powerful, and many have devastating side effects. In 1979, the state of California finally granted voluntary human service clients the right to refuse psychoactive drugs, but a suit to extend the same right to clients confined against their will in mental institutions has dragged on since 1978. In 1983, the state finally consented to a similar arrangement, much against the wishes of the psychiatric establishment. First, the client must be told of the potential effects of the drug, its side effects, and alternative treatments. Then the patient is asked for an informed consent. An independent medical panel will review cases where the client seems incapable of giving such informed consent, or where involuntary administration might preserve life or prevent serious bodily harm (Institutions, Etc., 8/83). This arrangement can still permit plenty of abuses but is a vast improvement over the previous ones. Similar law suits are pending elsewhere.

Conflict of Interest

Conflict of interest is one of the biggest obstacles to advocacy, but is poorly understood--especially when it is the most natural advocate, one's family, that has such conflicts and lets itself be ruled by them.

*The ca. 1983 head of the U.S. Occupational Safety and Health Administration had previously served as spokesperson for a construction company owned by his family that had been cited 48 times by OSHA for safety violations.

*Social Role Valorization theory implies all sorts of cautions when societally devalued people are deployed in service to other societally devalued people. In our past teaching and evaluation approaches, we have emphasized mostly the dangers of image impairment of such juxtapositions, of inappropriate role modeling, and of generating a subculture in which all members are societally devalued. However, Coping (6/83), a monthly magazine of the Maine Association of Handicapped Persons, has discovered an additional provocative problem. In Maine, a man who had polio about 30 years ago was provided services by the State Vocational Rehabilitation Bureau, helped through the university, and then hired and put in charge of deciding on home renovations for rehabilitation clients. In 1982, the man decided that his own house needed adaptations so that he could function better in it, because he had to use a wheelchair and there were many problems. In essence, in a procedure that seemed to be somewhat irregular, he approved $4000 worth of modifications to his own home. We will assume that these renovations were really needed and that the price was right, but the fact remains that there was clearly a conflict of

interest, and the whole situation looked very bad. Other handicapped persons began to raise the question why their own applications were denied, why they were approved for less costly renovations, etc. Also, the man's family income was $35,000, whereas many of his clients with equal and quite probably greater needs were poverty stricken. How can anyone be sure that if the man had not been holding his position, that his application would have been approved?

*It has recently come to light that a lot of parents of retarded female children in Iowa had them surgically sterilized. Amazingly, one major means utilized has been hysterectomy, even on children as young as 13. This often inflicts life-long physical anomalies on such females. Also, this type of indiscriminatory sterilization assumes total bankruptcy of supervision and control over a mentally incompetent person, and/or an opinion that such a person should be left free to be wantonly promiscuous. While such operations on minors merely because of parental demand have been illegal, nobody paid any attention to this until the Iowa Civil Rights Commission in 1983 sent a letter to hospitals reminding them. Some of the parents who had their children sterilized were key leaders of the Iowa Association for Retarded Citizens! All this is yet another example that parents can simply not be assumed to automatically act in the best interest of a child, and that children or mentally incompetent people will often need a guardian other than their parents, at least, in certain cases, ad litem. (Source item submitted by John Morris.)

*Now that infanticide and "mercy killing" are becoming increasingly legitimate, more and more family members of handicapped people are coming out of the woodwork in acknowledging their negative feelings toward their handicapped family member (often son or daughter) that formerly they would have repressed and acted out indirectly, perhaps by irrational behavior, overprotection, medical warfare against the handicap itself, etc. An example is what happened at the residential schools for the deaf of the states of Nebraska, Iowa and Texas. In Omaha, it was found that the students had been sexually abused by several staff members for many years, that a number of people had had inklings of what was going on, and had done nothing. The bad example of the staff also corrupted the morals of the pupils who engaged in all kinds of homosexual and heterosexual behavior among each other, even at an early age. A similar exposé took place in Austin. In Council Bluffs, across the river from Omaha, sexual abuse had been reported since 1978. Yet at the Nebraska school, 78 parents signed a statement criticizing the investigation there, claiming that their childrens' civil rights had been violated thereby. They denied the accuracy of the testimony given by their own children, and said that anyway, half the teenagers nowadays experience intercourse by the time they turn 19 and that homosexuality was a common experiment in adolescence (Institutions, Etc., 4/84).

The Need for Social Advocacy

*As early as 1843, Dorothea Dix used the term "legalized barbarity" to refer to what human services were doing to their clients/victims. It is amazing that the very language she directed to legislators could still be used today. "I tell what I have seen--painful and shocking as the details often are--that from them you may feel more deeply the imperative obligation which lies upon you to prevent the possibility of a repetition or continuance of such outrages upon humanity. If I inflict pain upon you, and move you to horror, it is to acquaint you to sufferings which you have the power to alleviate, and make you hasten to the relief of the victims of legalized barbarity."

So often, both decision-makers on the legislative, executive and judicial levels, as well as people in human services themselves, could indeed take measures to relieve the legalized barbarities of our day, but fail to do so.

*A study done out of the Harvard School of Business found that 15 top national business executives had 3000 to 7000 personal contacts each with people from all over whom they knew, and from whom they could ask and get favors. This finding staggers the imagination, and we muse sadly about the fact that so many of the devalued people we know may have had no enduring relationships in their lives, may have none beyond their current physical setting, and may not be able to call on anyone for favors (Coastal GAO Advocate, Fall 82). This is exemplified by a University of Minnesota report on residences for the retarded. It found that 63% of those in institutions had no friends. For retarded people in state-run group homes, the figure was a better but still pretty bad 43%. Contacts with non-handicapped people ran 4% in institutions and 16% in state-run group homes (Coastal GAO Advocate, Fall 83).

*The Commission on Quality of Care for the Mentally Disabled in New York is supposedly (in theory yes, in fact hardly) an independent body that is supposed to oversee the quality of services in state mental health and mental retardation facilities. It announced in 1983 that more than 100,000 reports are made to it each year of alleged irregularities at the facilities it is supposed to oversee. The Commission admitted that the most apparent outcome of its existence consisted of paperwork, and that few actual improvements resulted from it.

*Without noting any contradiction, the June/July 1984 issue of the US federal journal Aging noted in one article that people in nursing homes adjust relatively well, while reporting in another one that 503 existing state long-term care ombudsman programs in 1982 reported 41,000 complaints related to nursing homes and board and care facilities, not even including informal complaints that never got recorded.

*Below follows an abbreviated and slightly edited translation of the soliloquy of a wheelchair user, published in the journal of the German cerebral palsy association (Das Band, 4/83), "Expect I too much? Being handicapped often means also being alone. True, I have family that have loved me and cared for me, but I so very much want a friend. Expect I too much? A friend who understands my words and gestures, who listens at me and into me, and who sometimes has time for me. Expect I too much? A friend who puts his hand on my shoulder, and simply calls me up sometimes, and sometimes visits me, and perhaps occasionally goes somewhere with me. Expect I too much? So far, this friend has only existed in my fantasy and dreams as I have images of the telephone or the doorbell ringing for me. When it does not, I console myself with the thought that it might tomorrow. Expect I too much? I know that probably no one will ever say to me 'I love you,' but maybe somebody will say one day, 'I want to be your friend.' Expect I too much?"

*Human services have many ways of manipulating clients and their advocates. One ploy we heard of recently was for the government to send high-level officials to meet with "consumer" groups to hear their requests for appropriate services for handicapped people. After listening to the advocates outline what they needed, the government representatives said that they had to go back to their offices and conduct a "reality review." This meant that they now had to look at what services already existed and were available, and into which the handicapped people could be squeezed, rather than trying to create the services that were really needed. Thus, "consumers" were given the impression that they were being listened to, while in actuality, the governmental service providers had no intention of doing things differently for handicapped people.

*Meeting the needs of widows and orphans. A Syracuse school bus driver was indicted for sexually molesting a 4-year old handicapped girl on his route. The driver retorted that he had merely taken a special interest in the girl because she appeared to be neglected at home.

*A time to challenge. It has taken an awful long time to get public facilities, and some private ones, to reserve one or a few parking spaces for handicapped people. Usually, these are conveniently located in the parking space closest to an entrance. Unfortunately, we have noticed that this hard-gained boon for handicapped people is widely nullified by ruthless and selfish people who are not handicapped, and who will blandly park their own cars in these spaces. It is time for friends and advocates of handicapped people to challenge such malefactors.

The TIPS editor recently noticed in the handicapped parking space of a residential high-rise a brand-new Porsche sports car that might have cost $30,000, apparently parked there by its non-handicapped hedonistic driver. The next day, the TIPS editor saw another car parked in the same spot--but an able-bodied well-dressed young woman got into it. When the TIPS editor asked whether she was handicapped, she first sputtered "Yes," and after a few moments of confusion added, "In this building, this spot isn't being used by handicapped people." The editor stared her down and admonished her that she should not park in these spaces. She looked chastened. Of course, the best way to admonish malefactors is probably by using humor and/or thoughtful interpretation of what this is all about. A more forceful alternative taken by one of our friends has been to park his car in such a fashion as to block the one of the non-handicapped driver who parked in the slot for the handicapped. Where a parking area has an attendant, his/her attention can be drawn to such a parking infraction. If the attendant does not seem to care, the management of the facility might be approached.

The Need to Defend the Possessions of Devalued People-- Sometimes Against Theft by Their Supposed Advocates

*In our workshops, we emphasize again and again how devalued people are stripped of possessions, and how they are very likely to become or remain poor. Human services participate in this stripping process, as underlined yet again in a report of the Commission on Quality of Care for the Mentally Disabled of New York State, which found that there were inappropriate practices in the way in which state institutions have been managing over $35 million in personal funds belonging to clients in its institutions. For instance, the interest of the clients' funds was often, de facto, stolen by the state, and once a client left a state institution, it took an inordinate length of time to have his/her account released to him/her. Some institutions have apparently stolen hundreds of thousands of dollars apiece in this fashion. Of course, when a resident is deprived of the interest of his/her own money, then the purchasing value of the account diminishes because the increased cost of living is not offset by interest income. Where mismanagement does take place, residents, their families, or even the Commission itself, have hardly any legal recourse (Quality of Care, 3-4/84).

*The incredible story of the Ontario Public Trustee system. One of the most incredible large-scale legitimized perversions of advocacy that we have ever run across involves the operation of the Ontario Public Trusteeship. In 1919, an Office of the Public Trustee was established in the Canadian province of Ontario as part of its Ministry of the Attorney General. The Trustee was to administer the properties and estates of people in the provincial institutions for the mentally disordered or retarded, and of former such residents who were placed in other (including private) institutions, or who were released into the community but remained under some form of supervision of the province. The Trustee's office has also administered properties for a number of other persons who had been declared as suffering from some degree of mental incompetency.

In addition to managing properties of persons presumed to be incompetent, the Public Trustee also has had other duties: management of estates of Ontario residents who die both intestate and without heirs, and supervision of properties of certain corporations (e.g., charitable ones) that fall to the crown for various reasons. Apparently, this kind of work has been a minor sideline of the office.

All together, by May of 1981, the office had handled over 168,000 cases (i.e., people), of which over 118,000 involved active property administration. Approximately 5,000 people were "served" annually. However, not every person whose property falls under the committeeship (i.e., the direction) of the Public Trustee actually owns property. Thus, by May 1981, the Trustee's office supervised the properties of "only" about 18,000 (live) individuals (almost all of them in some kind of institution, mostly provincial ones), plus a total of about 28,000 estates and trusts. One can therefore assume that the vast majority of properties administered have been those of persons who died and left an inheritance--in many cases of persons who died a long time ago.

In former times, the institution population was more stable, but with the "revolving door" policies of recent years, a larger number of estates have come under the Public Trustee's jurisdiction. In the 1979-80 fiscal year, there were almost 2000 new estates. Additionally, in 1978, new mental health legislation came into force that would put under the jurisdiction of the Public Trustee even the properties of psychiatric "outpatients" who had been classified as incompetent. In the first year of this provision, this happened for almost 100 such outpatients. Earlier estimates had predicted that as many as 2000 might "qualify."

By 1980, the assets of the Public Trustee's office amounted to $219 million! The continued and rapid growth of these assets is apparent in the fact that this was about $30 million higher than in the preceding year.

The operation of the office of the Public Trustee of Ontario has probably been the most extensive of its kind in North America, as evidenced by the number of cases handled, the amount of property involved, and the size of the staff of the office. For instance, between roughly 1970 and 1980, the office had between 150 and 155 employees. Many of these have been attorneys and accountants, i.e., relatively higher-paid specialists. As of mid-1981, the staff numbered 98. Obviously, this sizable operation is costly. Operating costs in 1980 amounted to over $3,600,000.

A tremendous conflict of interest has been built into the operation of the Ontario Public Trustee, in that the office is expected to be self-financing, and does not receive provincial government funds. This means that it must charge its operating costs to the estates which it manages, regardless how well it manages these, or whether its management results in gains or losses to an estate. In fact, there does not appear to be any powerful external incentive for good management. Even the office's financial dependence on the estates is not a strong incentive for management quality, since there is a steady inflow of new estates. Another source of conflict of interest has been that the investments which the law permitted the Trustee to make have been heavily restricted to government-related securities. This constitutes a (second) conflict of interest, not so much of the Trustee's office as of the provincial government. In fact, these investments have been heavily in Ontario government and public utility bonds (to the value of about $89 million in 1980), which obviously might not be in the best interests of the individual estates.

As a result of the powers and policies of the Ontario Public Trustee office, it has been a steady profit-maker for its government--a highly unusual situation for a government office. For instance, between 1977 and 1980, the office earned approximately $3 million a year over expenses from its afflicted charges and their heirs.

The Ontario Public Trusteeship is obviously one of many systems that unconsciously but very busily contribute to the universal dynamic under which wounded and devalued people are stripped of their possessions, and involuntarily impoverished. This is all the more astonishing in that the trusteeship falls under the rubric of "protective services."

Some vignettes further underline the stripping process. We have been told privately that in cases where an institution resident might inherit a piece of real estate, such as a farm (that might be located far from the Trustee's office in Toronto), the office is apt to sell such an "inconvenient" and demanding asset well below its value, converting it into easily-handled cash. Next, the province might charge the resident's cost of institutionalization and "treatment" against these assets, which might thus soon be used up. Thus, despite an inheritance of a valuable piece of property, a resident might soon end up totally impoverished. We were also told that in the mid-1970s, one person was placed in an institution for a week for respite purposes, and while the bureaucracy usually moves with icy slowness, within that week, the Trustee had slapped a hold on this person's assets. In contrast, the bureaucracy moved extremely slowly in notifying the Trustee of the person's discharge from the institution a week later, and in the meantime, the Trustee was making dispositions and divestments of the assets. It took some energetic action by a protective service worker from another agency to bring the juggernaut process to a halt.

In another instance in the mid 1970s, a handicapped person who was going to a physician for a general health check-up that had nothing to do with the person's mental handicap was swiftly and high-handedly diagnosed and declared as incompetent by the physician, and again, it took a panther-like leap by a protective service worker to claw the person's assets away from the clutches of the Public Trustee, and to reverse this most bizarre process of railroading a handicapped individual.

*In California, when people were involuntarily committed to a state mental institution, the state would seize the assets of the person and apply them against the person's expenses, despite the fact that the person was detained involuntarily. A former client sued and, after five years of legal struggle, finally succeeded to have the practice declared illegal (Constructive Action Newsletter, 8/83).

*One way in which marginal people, especially formerly institutionalized ones, lose all their possessions is when they have a health crisis. They may have a seizure attack, get sick or their mental condition may worsen, and they may have to enter a hospital or institution. The day the rent is due, the landlord may not receive it, and then or sometime thereafter, some landlords simply put all the person's possessions on the curb to be picked up as garbage or by whoever wants them, and rent the room or apartment to someone else. The reason even crooked landlords will often put all the person's possessions on the curb rather than keep them is so that they will not be accused of theft. Sometimes, landlords will get, and are able to get, an eviction order in similar circumstances. When the person recovers, s/he not only has no place to return to, but also may have zero personal possessions left. In Syracuse, we see piles of possessions that look like they represent such persons on the curb all the time. One of the few times the newspaper documented such an event was in December 1983, when all this was done to a man of marginal social status who was lying in a coma in a hospital.

Counter-Advocacy

Some of the above vignettes illustrate what one might call "counter-advocacy," i.e., advocacy to do harm to vulnerable people. Here are a few more examples.

*An organization in Georgia is called Georgia Friends of the Mentally Ill, and its major effort seems to be directed at keeping people in mental institutions, and seeing to it that street people get put there (1984 news clipping furnished by Jackie Mincey-Cone).

*Another very maladaptive public awareness and attitude change effort was a television commercial by the Protection and Advocacy Office of the State of New York in July 1983. This ad showed a man who was described as handicapped chopping down a tree. The man happened to be one of the subjects of a film on community living made in 1980, called "Transitions." He had mild cerebral palsy, but it was not possible to tell from the scenes in the commercial that he was handicapped, nor what his handicapping condition was. After he chopped down the tree, the announcer's voice said, "You don't need to help--just don't get in the way." Such a commercial conveys a strong, if subtle, message that handicapped people are menaces, and are going to take what they want, by force if necessary. This type of approach is consistent with the very legalistic orientation of a number of Protection and Advocacy Offices, and coincidentally, apparently of the makers of the film "Transitions," rather than a persuasive and cooperative approach to improving public attitudes towards the handicapped through building community support and understanding.

*Here is a good example of a situation where there cannot be any winners. A New York City landlord leased four apartments to a local human service organization that placed 8 mentally handicapped people in them. When the lease was up, the landlord refused to renew it--a normative enough practice. However, the agency operating the apartments said that if the residents had to move out, they would be "left homeless" and institutionalized. Also, it referred to the refusal to renew the lease as an "eviction," rather than what it was, i.e., a refusal to renew a lease. The agency even got the State Attorney General and the Commissioner of Mental Health to go to court on behalf of the issue (This Month in Mental Health, 9/84). If the agency wins, this would unfortunately set a dangerous precedent. What landlord would ever again want to rent apartments to handicapped people being placed there by an agency if they could never be able to not renew the lease the same way they might not renew a lease for non-handicapped people? Furthermore, what kind of incompetency is involved if in as big a city as New York, an agency becomes so totally dependent on one particular landlord and site? Thus, what is being interpreted to be, and may appear to be, advocacy on behalf of afflicted people may really be a form of long-term disablement of community living.

Self-Help

Organized self-help can be a form of self-advocacy, though it really often involves mutual help among people who carry the same burden of affliction or devaluation. Self-help is laudable if it is not perverted--as it is increasingly becoming.

*Harper's of 6/84 published a list of about 50 voluntary associations that it called "synthetic families" that participated in a "self-help fair" in 2/84 in San Diego. The list included associations of parents of murdered children, parents of William's Syndrome children, a Pre-menstrual Syndrome Group, a group of people who have had brain surgery, and so on. A whole series of these groups had something to do with bad eating habits, and another entire cluster had something to do with all kinds of sex problems and abuses, e.g., a group of families that had been involved in incest, a sexual assault group, etc. To some degree, it is good news that such groups exist. At the same time, the list is saddening because it is a litany of our social problems that people seek to combat by banding together. Also, the particularism expressed by the formation of such extremely specific groups is discouraging.

Tongue only partially in cheek, a Time (7/11/83) article claimed that in Berkeley, California, there are more groups trying to meet each night in order to "support or empower" each other than there are places for them to meet. Such groups may use media ranging from meditation to martial arts, some form of group therapy, and all the way to sword dancing.

*Among the self-help groups that seem to overdo it a little bit are Today For Singles, Inc., an association that introduces people with herpes to members of the opposite sex that also have herpes, African/American Parents and Grandparents without Partners Society, and a dance club for only tall people where women must be at least 5'10 and men 6'2 (NCR, 2/3/84).

*In Berkeley, California, there is a group called the Frog Prince Conspiracy, which is a "self-help" group for people who are extremely attractive. It is a group "where the lovely can go to bemoan the problems they suffer from being too good-looking." However, the criteria for joining the group are subjective, and the two founders of the group have said that sometimes, some people have shown up for meetings who "clearly didn't belong," that is, who were not attractive enough. One of the co-founders also said that they had thought about forming a group for ugly people, but rejected the idea because it was "depressing. I like to be positive and upbeat. I'd rather work with people who have lots of potential." (News item submitted by Joe Osburn)

*Self-help and similar associations form around ever more esoteric conditions. From the October 1983 issue of the Exceptional Parent, we learn of an effort to form an association of parents of children who have--believe it or not--Ectrodactyly-Ectodermal Dysplasia Clefting syndrome (Exceptional Parent, 10/83).

*Another self-help group which, we hope, will remain small, consists of Catholic women who have had sexual affairs with priests.

Language Perversions & Degradation

This is an age in which language is being totally debased so that one hardly knows anymore what is being communicated. This process robs people of their capacity to both express and deal with truth, and permits all sorts of evils to infiltrate. An example of all this is the reaction of many advocacy bodies on behalf of devalued people to previous language abuses, who have fallen to the opposite perverted response of using language that pretends that people with problems or handicaps don't have any. For instance, some people would abolish the use of terms such as "mental retardation" and no longer talk about people being mentally retarded. Going far beyond confronting these, they condemn the use of terms such as afflicted, poor, case, epileptic, normal, crippled, deaf mute, courageous, spastic, suffering, victim, unfortunate, cerebral palsied, and confined to a wheelchair. Some of these words are perfectly useful and descriptive, while some can be used either poorly or well.

One term the TIPS editor has been using is "confined to a wheelchair." Advocates say one should say "...uses a wheelchair," but it seems absurd to equate someone's use of scissors, pens, cars, or gloves with the limited choice of being in bed, on a chair, or in a wheelchair. So when a person spends more than half of his/her time in a wheelchair because of lack of any viable other alternatives, then one is indeed confined, notwithstanding the fact that one may be liberated from the bed.

Wise advocates will steer that middle course of language use (a) which is not unnecessarily devaluing, (b) which observes the guidelines of the conservatism corollary of Social Role Valorization (formerly called normalization principle) in bestowing value to people at image-risk, but (c) which eschews terminology, communication and language that is content-less, that forces people to speak unnaturally and inhibitedly non-spontaneously, or that otherwise debases meaning and communication, especially meanings which are crucially important in one's mind, or which are in need of communicating to others. Furthermore, wise advocates will not be ruled by what the current craze of the "advocacy-chic" is. Those who succumb may find themselves in the situation of a person who was speaking about retarded people, was intimidated by retarded people's demand not to be referred to as retarded, and ended up saying "people who have you-know-what."

Another perversion is to refer to handicapped or retarded people who manage fairly well on their own as "self-advocates." An example of this absurdity is a picture caption, "Five self-advocates having lunch." The amazing thing is that most competent and independent citizens would never be referred to as self-advocates. For instance, the TIPS editor would not qualify for this label --but a handicapped person who shows normative or merely unexpected accomplishments may be referred to by such a term. The (National) Association for Retarded Citizens scheduled an international symposium on the quality of life for October 1984, and its registration form listed three types of potential participants and rates: unspecified registrants, student registrants, and "self-advocates," the latter almost certainly being a euphemism for retarded persons. However, since the vast majority of people are, in fact, self-advocates, theoretically it would really be the non-retarded people who could sign up as such at $10 while the retarded ones would have to sign up in the unspecified category for $90. This registration format also implied that all retarded people are poor and could not even afford the student fee, and that all students could afford more than any retarded person. We appeal to our readers to free themselves from such absurd language uses, and to accept the fact that there is no way to avoid using language to refer to unpleasant realities, or to realities which some people wish did not exist.

Lawyers Out of Control

*In what must surely be one of the most bizarre out-of-court insurance settlements in American history, the heirs of a family that died in a plane crash were awarded $375,000. The insurance company settled when it discovered that the plaintiffs were going to make the point that the victims had been watching their plane take off on a video monitor in the passenger compartment, and that for a period of perhaps 30 seconds, they could see that they were going to crash. The plaintiffs were going to show an animated re-creation of what the victims might have seen. The settlement was made to recompense the heirs for the horror that the victims presumably experienced while watching this video monitor. One bizarre element here is that the heirs are paid for the few seconds of terror experienced by the family, and that the benefits of this terror should go to the heirs to the tune of over $10,000 for every second of terror (Syracuse Herald Journal, 23/5/84).

*German literature has a genre called gallows humour or gallows songs. These seem very appropriate in instances where extreme tragedy is surrounded by incredible absurdity.

A man with a history of extreme violence had been let in and turned out of the Hutchings Psychiatric Center in Syracuse 7 times in a 2½-year period. When the man returned and announced that inner voices were telling him to rape someone, he was nevertheless sent back out on the streets to a "diversional" day program. Shortly thereafter, he stabbed to death a counselor in the day program. The psychiatric center was ruled negligible and ordered to pay the widow $133,000 in damages. Because the victim moaned briefly after being stabbed, she was awarded an additional $10,000 for the pain and suffering he presumably experienced prior to death. Apparently among the many lessons taught to society by this episode are (a) that one should try to moan before dying because this might benefit one's heirs, or (b) surreptitiously pinch a dying person somewhere so as to elicit a moan if one wants to do good to the person's heirs (Syracuse Herald Journal, 7/5/84).

*Shall we kill all the lawyers? A 65-year old woman in New York bought a down jacket for her husband. The sales personnel forgot to remove a security tag from the item, thereby triggering the shoplifting alarm on her way out. The event is one that occurs about 20 times a day, and is probably the price one has to pay for living in our kind of society in which mutual disablement is the norm. When

confronted, she produced proof of purchase, but the personnel forgot once more to remove the security tag and when the little old lady left the store, the alarm rang again. Thereupon, the store employees erupted into laughter--which cost them dearly, because the lady sued, claiming that the event brought on crying spells, nervousness and insomnia. Her lawyer argued that she was snow-capped, had spent 3 years in a nunnery, went to church on a regular basis and taught piano--all these things apparently being evidence of her fragility. An obviously insane jury awarded her $600,000, and even after a judge ruled that this was excessive and reduced it to a mere $175,000, all of this can merely serve to give people the idea that they should engineer events of this nature in order to retire wealthy for the rest of their lives (AP in Syracuse Herald Journal, 6/5/84).

Citizen Advocacy Perversion or Subversions

*In Franklin County, New York, there is a corporation providing vocational, prevocational and residential services to handicapped people which calls itself Citizen Advocates.

*A multiple perversion of citizen advocacy implementation efforts was noted in a 1983 announcement in a Mennonite journal, where a citizen advocacy program appealed for a Mennonite volunteer to serve as a local citizen advocacy coordinator for a term of 1 to 2 years and also conduct direct case advocacy. This recruitment effort violated the principle that if at all possible, citizen advocacy coordinators should be deeply rooted local people, that they should be recruited with job stability in mind rather than with built-in discontinuity, that they should never conduct what amounts to paid case advocacy.

*Yet another attempt to control citizen advocates took place in Manitoba where the provincial department of Community Services and Corrections, and the provincial Public Trustee's office, have tried to establish a procedure whereby the recruitment, matching and activities of citizen advocates would be controlled by a so-called "IPP team," and would undergo an unbelievably bureaucratic process of review on several levels of officialdom. In those instances where an advocate would be approved by the IPP team, the advocate would have to function as part of that team and "work within it." So far (3/84), the Manitoba Citizen Advocacy body has rejected this scheme.

Other Social Advocacy Perversions

Many protest actions lose their relevance, impact or even moral coherency by being poorly focused, by the issues not being explicated to witnesses, and by protestors allying themselves incoherently with other groups. A gross example of this is a "stop the city" demonstration in London interpreted by peace groups as a "protest and carnival against war, oppression and exploitation" in which police ended up arresting what they described as 200 "anarchists, homosexuals, animal lovers, and punks," many sporting neon hairdos, and in which two policemen were injured, one by being bitten (UPI, 3/84).

Miscellaneous Social Advocacy-Related Facts, News, & Insights

*Educational institutions are by far the biggest recipients of private foundation monies (42% in 1982), and furthermore, 24% of all foundation monies went to capital support (meaning buildings), while 20% went to program development and 21% to continuing support. Of all charitable expenditures, 76% were made by only 15 charitable organizations. Only 15% of non-profit organizations were founded prior to 1930, while 46% have been formed since 1971 (Responsive Philanthropy, Spring 1984; news item furnished by Doug Mouncey).

*Anything to win. A citizen advocacy officer was recently asked by the employee of a radio station how to spell "advocacy." Unfortunately, the questioner wrote it down as "abvocacy," and then wanted to know whether it was a disease (Vignette submitted by Gregor Smith).

*In early 1984, the oldest citizen advocacy program, the one in Lincoln, Nebraska, had three advocates who had served 13 years, three who served 11, two who served 10, and then an increasing number for almost every year since.

*A handicapped participant at one of our workshops once said that "the handicapped person has to look beyond the non-handicapped person's not looking beyond the handicap." In other words, the non-handicapped person may err by not seeing beyond the handicap of a handicapped person. However, the handicapped person can also err by getting excessively wrapped up in his/her recognition of this phenomenon, thus really being no different than the non-handicapped person who cannot see beyond the handicap.

*Lynn Breedlove cited a study by Brad Hill of the Minneapolis ARC citizen advocacy program that found one or more studies to support each of the following findings.

1. 1 of 3 key obstacles to a person's success in independent living is loneliness and a lack of support systems.
2. Whether or not a mentally retarded person has a suitable friend has a big effect on whether the person spends his/her leisure time in "active, goal-directed" activity, as opposed to "passive activities like napping, watching TV, or gazing."
3. Related to #1, deinstitutionalized persons with no friends are at substantially greater risk of returning to the institution than are people who have friends.
4. Retarded people with friends had higher self-concepts than retarded people without friends.
5. Retarded adults who had non-retarded friends showed better social-educational skills (reading, writing, manners, helping at home) than did the other subjects.
6. Friendships between retarded people and non-retarded members of the community usually do not come about naturally.
7. Retarded people, whose social contacts are often limited to other residents within their own residential facilities, workshops, or day programs, continue to experience problems with social, family, and leisure activities.
8. The single largest problem reported to interfere with leisure activities was that there was no one available to accompany residents for various activities.
9. Only 27.3% of community facility residents and 11.3% of residents of public facilities were reported to have a friend among their peers. Few residents in either public or community facilities had any regular social contact with non-handicapped peers. 42% of community facility residents and 63% of residents of public facilities were reported to have no friends at all.

The Deathmaking Front

Infanticide

*Nat Hentoff, the editor of the Greenwich Village Voice, pointed out that the proposal of the American Medical Association to let hospitals and physicians develop their own guidelines for the treatment or non-treatment of handicapped infants amounts to a "local option," according to which a locality would decide who would live and would die, much as they might decide on whether beer or wine should be sold in grocery stores (Washington Post, 29/6/84).

*In our last TIPS issue, we warned of false expectations regarding the ongoing attempts to amend the 1974 federal Child Abuse Prevention and Treatment Act as a means of stopping infanticide of handicapped children. Virtually all the organizations that had promoted and opposed federal attempts to prevent such infanticide during the last two years endorsed the amendment, which can surely not be a good sign. Since then, the amendment passed the Senate in July by an 89-0 vote--another sign that no good can possibly come from it. The newsletter of the Association for Persons With Severe Handicaps headlined the announcement as "'Baby Doe' Amendment Passed," again giving the impression that the problems are now solved. It called this a "major piece of legislation that represents a remarkable act of cooperation on the part of a diverse group." People who naively put their hope in these sorts of efforts in the face of the societal realities stand to learn a lesson, if they are willing and capable of learning.

*When a child is born with spina bifida, surgery, if feasible at all, should be attempted within the first 24 hours because thereafter, it becomes virtually impossible to control the bacteria that build up on the human skin, and to which children with this condition are extraordinarily susceptible. In 1983, it was estimated that 10-15% of children with some form of spina bifida were being denied treatment, that half of these would be dead of infection within three months and that the other half will continue to live in far worse condition than if they had been treated.

*Children with spina bifida at the State University Hospital in Iowa who were denied medical treatment were said to be "targeted for non-treatment" (1984 E & N Public Service Video Cast).

*In the series of 36 infant deaths at Toronto's Hospital for Sick Children, one nurse had been identified as being the only one on duty in all of the 28 or 29 most suspicious deaths, and some of these deaths supposedly resulted suddenly after the nurse relieved other nurses. This particular rash of deaths--not the first one at that hospital--occurred in less than a year, between June 1980 and March 1981. During one episode, 6 babies died within a span of 7 nights. One of the speculations has been that one of the nurses committed murder in order to discredit another nurse, but obviously, much more than a desire to discredit someone else is needed in order to commit somewhere between 28 and 36 murders. One such suspicious death occurred the very first night the chief suspect returned from her honeymoon. (This can give one frightening thoughts about what the current wave of hatred of reproduction could do to women once they have learned to harbor such hatred or dread, and are then expected to save the lives of fragile infants.) The deaths are believed to have been caused by the administration of a heart drug (digoxin) that is difficult to detect. An interesting and revealing element of the case is that there was not enough basis for a legal prosecution, but instead there was a royal commission investigation. Even nurses who had not come under suspicion did not fare very well in the inquiry. After a series of deaths had occurred, a number of them met privately and agreed to "stick together," which meant that they were quite willing to undermine efforts to get at the truth even though some of them, according to testimony, suspected that there was murder going on, which one of the nurses referred to by the detoxifying term "intervention." This nurse, who at one time had been a suspect but then seems to have been adequately cleared, had also been recorded as making glib remarks about some of the deaths. Civil rights activists went up in arms because they thought that the investigation amounted to "trial by investigation" which would leave the reputation of suspects permanently smirched without an opportunity to clear themselves. While there is an element of truth to this, we see here once more a situation where there is more concern with the welfare of the survivors than with justice for the murdered.

Abortion

*In Philadelphia, an abortion was performed on a mother who had been pregnant 32 weeks, i.e., 8 months. Even though babies born at 8 months are often saved nowadays, no provisions were made to abort the baby alive, or to care for it if it should survive the abortion ordeal--which it did, though only for a few hours (Philadelphia Daily News, 20/9/84, source item supplied by David Schwartz).

*In Alberta, a man had listed his children as beneficiaries on a life insurance. He died when his wife was one month pregnant and the insurance company refused to pay the child's benefit when it was born on the grounds that the child had been merely a fetus, and therefore not a person, at the time of the father's death. The insurance company was upheld by one court, but overruled by the Alberta court of appeals (Pro-Life News, 3/84, submitted by Doug Mouncey).

*With increasing frequency, the Index Medicus, the major abstracting service in the field of medicine, has been listing articles that describe the use of live aborted babies in medical experiments, including tests of life support systems, observation of functioning organs, evaluation of death-inducing methods, and body and organ transplants (Seeds, 6/84).

*When one hears the term "fetal monitoring techniques," one probably thinks of ultrasound that is sometimes used to track the baby's progress before and during birth. However, to our astonishment, we recently heard the term used for the new chorionic biopsy technique which will probably replace the bulk of amniocentesis as a major precursor to the performance of abortion (The Human, No. 1, 1984).

*The pro-abortion movement has launched a new strategy. Prior to 1984, one virtually never heard Western opinion leaders advocate abortion as a means of population control. Suddenly, during 1984, one began to encounter all kinds of arguments that without abortion, world population problems would become uncontrollable, and that anybody who was against abortion was either unrealistic or trying to keep Third World nations down. We must expect a great deal more propaganda along these lines.

Crowding and overpopulation are for real, and in some instances, they are desperate problems. Those pro-life advocates who try to downplay the problem of world population are indeed unrealistic. However, killing is no way to solve problems. Violence can only beget violence.

*A rare bit of positive news on the fate of the unborn is a ruling of the Massachusetts State Supreme Court in August 1984 that a driver who causes the death of a viable fetus can be prosecuted for vehicular homicide, because "an offspring of a human parent cannot reasonably be considered other than a human being and, therefore, a person, first within and then, in normal course, outside the womb" (NCR, 7/9/84).

"Euthanasia"

*A new landmark toward "euthanasia" has been passed. In October 1983, the California Court of Appeals ruled that a vital feeding tube could be removed from a comatose patient upon the request of the person's close relatives. The decision was underpinned by a quality of life rationale. There are at least three problems with this ruling: (a) the procedure condemns the patient to starvation or dehydration, (b) the procedure could be performed even though the patient has not left any indication of his/her own will in the matter, (c) the decision could be made on the basis of the judgement of close relatives who have conflicts of interest , and sometimes even harbor death wishes toward the afflicted person. With this precedence, similar reasoning might be applied to the withdrawal/withholding of respirators, antibiotics, or other relatively simple, straightforward, non-extraordinary basic medical life supports (The Human, 5-6/84).

*A California male nurse was convicted in March 84 of having murdered 12 elderly patients with overdoses of a heart drug at two hospitals, in what was termed one of the most complex medical and legal cases in California. The 12 deaths may only be the tip of the iceberg, insofar as 60 sudden and mysterious deaths of patients were identified at hospitals in three southern California counties where the nurse had worked. In June, he was sentenced to death, but it is extremely unlikely that the sentence will ever be carried out. As we have noted many times before, "euthanasia"-related killings hardly ever come to the courts, and if so, rarely lead to convictions, and if so almost always draw light sentences. Thus, this case is quite unusual.

*A woman in Greenwich, Connecticut, claimed she smothered her mother who was terminally ill of cancer, putting a pillow over her face and pinching her nostrils as a way of "helping her to Heaven." However, the physician who performed the autopsy ruled that the mother had already been dead, and the prosecutor then refused to sign charges. In light of the long history of sympathy for so-called mercy killers, one can be skeptical about the physician's statement, and the event certainly proves yet once again how widespread "euthanasia" sentiment is (Syracuse Herald Journal, 13/6/84).

Killing Sans "Euthanasia"

*In Florida, a mother was convicted of dumping her handicapped 19-year old son who was wearing heavy braces and no life preserver over the side of their boat during a canoe trip so that he drowned. She had also been charged with administering poison to him. She was the beneficiary of a sizable life insurance policy.

Deathmaking Via Abuse

*A mentally retarded young man had been placed into the home of "caretakers" in Fulton County, NY, and for two years he was subjected to abuses such as being forced to roll in hot charcoal, being burned with cigarettes, being hung from ceiling rafters, being tied naked to his bed, being beaten, and being coerced to engage in self-abusive and sexually deviant behavior--reportedly all for the amusement of his caretakers. Even though this abuse was reported to various authorities who held futile meetings about it, including the county's Protective Services for Adults, nothing was done by any of them, and at age 21, the young man died as a result of further abuses (Quality of Care, No. 21, 1984).

*The US Department of Health and Human Services said in August 1984 that conditions in state institutions for the retarded across the US are "appalling." In one inspection of 17 such facilities in July 1984, all were found to be substandard, in nine, there were major health and safety deficiencies, and some of these were described as "life threatening." Overuse of drugs was very common. Whereas it is considered alarming to find 20% of residents on major tranquilizers, one facility had 36%. New York State alone was fined $59 million for code violations. There now are 100 federal inspectors for the nation's 2200 state MR facilities. The Medicaid money that supports them is the fastest-growing item in the Medicaid budget, taking $3.9 billion in 1983, for 132,000 people (UPI, 1/8/84, source item supplied by Chuck Burkhouse).

*More than 250,000 Canadian school children are being given drugs to curb their unruly behavior ("Man Alive," CBC-TV program, 3/83).

Deathmaking Through Marginalization

*When unemployment is high, people are generally willing to work at lower wages, which benefits some of the people in business. When a report came out recently that unemployment had jumped from 7.1 to 7.5% in July 1984, there was a great increase in the trade of stock the next day. In other words, investors decided that this was a good opportunity to buy stock because higher unemployment also increased the chances for profit (NCR, 31/8/83).

*An emaciated 73-year old woman in New York, evicted from her apartment, despondent, and not knowing what to do, threw herself in front of a subway train. Because she was so tiny and fell between the tracks, she survived. However, had she died, one would have attributed her death very narrowly to being run over by a train as a result of suicide, rather than as the culminating result of systematized, large-scale and evil marginalization of aged and devalued people. Thus, neither in terms of official records nor even in people's minds would her death have entered the category of systematic deathmaking of devalued people that we have been talking about. Another lesson to be learned is that after her suicide attempt, the powers that be subjected the woman to a psychiatric examination. The imperial structures are quite capable of using human services to victimize the oppressed, but are unable to utilize equivalent resources to alleviate their plight.

*Hypothermia, a condition of abnormally low internal body temperature, kills over 10,000 people each year, a large proportion of them elderly ones who can become hypothermic when the indoor temperature goes down to below 65F--a temperature at which most other people can be quite comfortable if they are well dressed (Aging, No. 343, 1984, p. 3).

*After 491,000 extremely vulnerable Americans had been deprived of their federal disability payments between 1981 and 1984, even the consciences of some very conservative legislators were roused. Republican Senator Heinz of Pennsylvania called the federal policy a "holocaust of the nation's disabled" (Newsweek, 24/9/84). A federal judge noted that 49% of the cases in which the federal Health and Human Services Department denied disability benefits to people during the last half of 1983 were reversed by courts, proving that "such a rate of reversal throughout the land is staggering and paints an undeniable picture of a heartless and indifferent bureaucratic monster destroying the lives of disabled citizens, and creating years of agony and anxiety." One of the hundreds of thousands of people who was reinstated was a veteran who had been shot through the head in Vietnam in 1968 (UPI, in Sy acuse Herald Journal, 8/6/84).

*A man who resides on a heating grate outside the Daughters of the American Revolution Building in Washington, DC was prohibited from registering as a voter by the local elections board on the basis that the board did not have authority to register persons without a fixed address. In essence, this constitutes yet another step in the denationalization of poor and homeless people--in the modern age, frequently an intermediate step prior to their extermination (NCR, 27/4/84).

Resources

*Readers interested in the content of this issue may also be interested in the monograph by the TIPS editor, published within the last year, entitled Reflections on the Status of Citizen Advocacy. It contains the author's conclusions on where some of the strengths and weaknesses of citizen advocacy (CA) have been, why CA offices have been slow to establish certain types of matches, and what can be done about it. The monograph, cosponsored by the National Institute on Mental Retardation and the Georgia Advocacy Office, is available in Canada for $3 Canadian from NIMR (York University, 4700 Keele Street, Downsview, Ontario, Canada M3J 1P3) and for $4 US plus postage & handling (minimum $2) from the Onondaga CA Office (956 Cumberland Avenue, Syracuse, NY 13210).

*Kristjana Kristiansen, together with three associates, has announced the founding of the Nordic Institute for Service Systems Planning and Change, abbreviated NORPASS, a form of near-polar Scandinavian Training Institute. They inaugurated it by holding a Social Role Valorization workshop in Iceland--not the biggest, maybe not even the best, but certainly the most northern.

Upcoming Workshops

*Especially relevant to this TIPS issue on social advocacies is that a workshop is planned for June 28, 29 and 30, 1985 in Syracuse on "Fidelity to Citizen Advocacy." The event will review why citizen advocacy (CA) offices are so easily diverted from the basic CA ideal and schema, and will present two response strategies: how to embed CA firmly in the local community, and how to develop a "communal" rather than an "organizational model" of CA. Interested parties should request a detailed flyer from us.

*The TI is giving another Sanctity-of-Life workshop January 24-26, 1985, in Edmonton, Alberta. One can register with George McRae (Grant MacEwan College, Mill Woods Campus, 7319-29th Avenue, Edmonton, Alberta, Canada T6K 2P1, 403/462-5551) for $150 Canadian, and receive a detailed flyer from them or the Training Institute.

Politics & Elections

*The TI has long taught that one should have a preferential bias toward the oppressed, but that one should not endorse any perversions promoted by the oppressed. Good cannot be the fruit of evil. If both parties in a conflict are perverse, then one stands aside--or in the middle.

Accordingly, the TIPS editor will vote for neither presidential candidate in November 1984, because each promotes deathmaking. While both support the arms race, each additionally is committed to other forms of deathmaking. One is an enemy of the handicapped, and of the poor of the world, the other defends abortion and, apparently, infanticide. Thus, our comments about the current (Reagan) administration are not meant to imply a promotion of any other candidate. By not voting, one lets the world know one's lack of faith in the prevailing arrangements.

A 1940 Election Dream (Reprinted by permission of the Catholic Sun, 3/10/84).

The time is 1940, the place Berlin; a candidate for the Reichstag is being interviewed.

Reporter: Herr Schnaus, what is your position on the Jewish Question as a Catholic Candidate for the Reichstag?

Herr S: As a Catholic I have absolutely nothing against the Jews. Some of my best friends were Jews but I believe that I have the obligation to uphold the laws of our country.

Reporter: Well, it is pretty well established that a large number of Jews have been sent to Concentration camps and many, many have been murdered under the laws of the country.

Herr S: Yes, I am very personally opposed to what is taking place. Murdering innocent people is against the fundamental principles of my Catholic faith but I don't believe that I have the right to impose my beliefs on others.

Reporter: But Herr Schnauss, you are an especially influential member of the Reichstag, I would think you would have some influence on the actions of our society, maybe even work to get the law changed.

Herr S: But the law is very popular. Polls indicate that 64% of our people are in favor of the policy. After all, I have a responsibility to the people who put me where I am. How would it look if I just went off and acted on my own convictions?

Reporter: Do you have any idea how many Jews might be involved? I understand the number is up in the millions.

Herr S: What do numbers have to do with anything? We are discussing a principle here. One or ten million, it doesn't matter, this is a law of our nation and it should be applied and upheld.

Reporter: What about the question of morality, right or wrong? After all, this is just another form of murder.

Herr S: Morality doesn't exist in a vacuum. You must weigh the importance of the individual against the common good. Getting rid of an undesirable element that threatens the stability of the Reich is far more important than the individuals involved.

Reporter: But what about the Jews, how do you think they feel about this?

Herr S: They are helpless, they have no voice, no political base and as a consequence they do not become a factor in the political equation.

Reporter: You stated earlier that as a Catholic you found the law objectionable. Isn't that sufficient reason for you to actively oppose it?

Herr S: Precisely the point. I have no right to impose my religious views on others. Suppose the commander of some concentration camp doesn't agree with me. What right do I have to force my view on him? He is only doing his duty and enforcing the laws of the land.

Reporter: Does it occur to you, Herr S., that this is not a political or judicial question at all but a question of the fundamental nature of man and humanity? That what you would be defending is not a religious position at all but human life which transcends all other elements of society?

Herr S: We have handled that question quite adequately. The Jews are non-persons. The issue of humanity doesn't even arise. Everything we are doing is quite logical. But I must admit that if this was not the case, I would be obliged to defend the fundamental rights of these people in every and any forum and actively try to have the law changed. Since that is not the case my position is absolutely secure.

*According to a 400-page study, entitled The Reagan Record, issued by the Urban Institute of Washington, a non-partisan think tank, government policies under the Reagan administration have resulted in a transfer of $25 billion of income from the lower to the top economic strata in the US. This involved a decline in 8% of disposable income after inflation in the poorest 20% of US families, and a rise of 9% in the wealthiest 20%. The middle income group remains within 1% of its previous status (NCR, 31/8/84).

*The tax burden on a family of four at the poverty line has gone from 4% of income in 1978 to 10% in 1983 (Newsweek, 10/9/84). Half of the poor were in families headed by single women.

*Empire language. In August 1984, unemployment was 7.5%, the same as it had been when President Reagan had taken office three years earlier, and the same as the month before. Ordinarily, employment goes up during the summer and down in the winter, but a White House spokesman said, "It is encouraging news that unemployment rates remain stable." Had unemployment increased by 10%, he would probably have said, "It is encouraging news that unemployment has increased by only 10%."

*One reason the US Federal Government is cutting back all kinds of supports and subsidies to its Indian tribes is that it is trying to force them to open up their lands to mining and drilling (Environmental Action, No. 2, 1984).

News: Good?

*A Syracuse newspaper was accused by some readers of being "down on everything... and never in favor of anything." This stung the editors so much that they issued an editorial that complained that "unfortunately, it is the very nature of news that most of it is bad. To reverse the old saw: 'good news is no news.'" It noted that no one cares to know that a particular commuter got home safely to his family, or that a public servant was doing what s/he was supposed to do. They only become news when they wrap themselves around a tree on the way home or get caught with their hand in the till. "Let us hope that we never reach the point where common decency becomes so rare that it commands public notice." Then, grasping at straws, it cited three items of good news: that there will be an election this fall, that the country is at peace, and that school would be opening in a few days (Syracuse Herald Journal, 3/9/84).

We sympathize with the newspaper, having commented on the same problem repeatedly in TIPS, partially in response to the groans of some of our readers. However, we would add that it is not merely in the nature of news to tend to be bad, but that the times are such that common decency in human services may indeed command public notice.

To exemplify the point, we cite the following item.

A certain Newfoundland arctic Indian village has 70 houses, inhabited by 139 families. The provincial government decreed that when people receiving welfare lived together, their welfare payments would be reduced because they would presumably live cheaper. This automatically means that in areas where housing is already short or outright nonexistent, the poor are doubly penalized. Four social workers refused to implement the government decree and were dismissed. One of them nonetheless decided to continue living with the Indians as a sign of solidarity.

We interpret this event to be good news in that a human service worker took a firm stand, refused to do what was wrong, accepted the consequences, and remained in solidarity with the victims. Of course, the bad news is that big government continues its oppression of those on the bottom (Seeds, 6/84).

*In June 1984, the Plymouth Developmental Center outside Detroit, Michigan, closed its doors. This event has great poignancy for the TIPS editor who worked there in 1963-64 as Director of Research and Training after he came back from post-doctoral study in England. I was on a team of staff members that was asked to help design several of the buildings, and virtually pleaded on my knees with the other team members not to go ahead with some of these plans and designs. My fruitless opposition to these building plans was one of the things that marginalized me and prompted me to leave. At that time, there were about 600 employees among which I was able to identify only 3 others who were strongly positively ideologized and personally committed to the retarded residents. Community groups had been bringing truck loads of toys to the institution, and after the toys were smilingly received at the front door, one of the higher executives had them transferred into trucks at the rear and carted away to a dump because they would merely "clutter up the floors" and "be destroyed by the residents within a day or so anyway." The institution continued to grow to an eventual peak of 1200, and even though it was new, it was beset by scandals throughout much of its relatively brief life. Nevertheless, a fair number of its senior professional staff members obtained roles of prominence in their fields.

News: Bad

*How thoroughly citizen advocacy is disdained in human services was underlined yet once again by the 1983 publication of a book entitled Social Support Networks: Informal Helping in the Human Services, by two authors with high reputations (Whittaker & Garbino). It entirely failed to mention citizen advocacy, although CA has been around since 1969. (Drawn to our attention by Genevieve Fairval)

"HOUSEKEEPING ANNOUNCEMENTS"

TIPS Editorial Policy. TIPS comes out every other month, and contains articles, news, insights, reviews and viewpoints that relate to the interests and mission of the Training Institute. At the present, this mission has to do with reading "the signs of the times," and interpreting their meaning for human services. While TIPS is mostly concerned with phenomena and developments that have to do with human services, reading and telling the "signs of the times" necessitates that TIPS also address some of the larger issues which affect our society and the quality of life on earth, as well as the ways in which decisions are made in our society, because these higher-order phenomena will eventually express themselves in human services in various ways, including in human service values and funding. Usually, each TIPS issue will focus primarily on one specific theme. TIPS addresses relevant developments whenever and wherever they occur, so disclosures of adaptive or horrific developments promoted by a particular political party or government should not be taken as partisan political statements. We assume that subscribers are people who lead hard lives struggling against great odds, and are aware of many shortcomings in human services. Thus, we try to inject levity into TIPS so as to make subscribers' lives more bearable (or less unbearable, as the case may be), even if not deliriously joyful. In fact, the "signs of the times" are depressing, and thus some TIPS content is in need of occasional levitation. TIPS tries to report developments truthfully, but since it gets many items from other sources, it cannot be responsible for errors contained in original sources. Specific items from TIPS may be reproduced without permission as long as the full TIPS reference is cited/acknowledged, and as long as only small portions of a TIPS issue are so reproduced.

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Invitation to Submit Items for Publication. We invite submissions of any items suitable for TIPS. These may include "raw" clippings, "evidence," reviews of publications or human service "products," human service dreams (or nightmares), service vignettes, aphorisms or apothegms, relevant poetry, satires, or brief original articles. We particularly welcome items telling of positive developments since bad news is so frequent as to be the norm. Send only material you don't need back, because you won't get it back. If we don't goof, and if the submitter does not object, submissions that are used will be credited.

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